

Pregnancy and parenthood

Fact Sheet

Multiple
Sclerosis
Trust



Information

Education

Research

Support

Pregnancy and parenthood

Date of issue: February 2011

Review date: February 2012

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Introduction

MS is most often diagnosed between the ages of 20-40, the age at which many people may be thinking of having a family. Deciding whether to start or add to a family is often a complicated process, and MS raises a host of other questions to consider.

Many people look forward to having children. However, emotions may be mixed, and most have concerns about their current or future ability to take on the practical, emotional and social responsibilities that children bring. There are no straightforward answers to these questions. For people with MS, these feelings may be reinforced by doubts from friends, relatives and even some health professionals.

This factsheet aims to summarise the research into the health aspects of MS and becoming a parent, and to help you discuss issues and concerns with the health professionals you see, such as your MS nurse, midwife or GP.

1. MS in the family

A very common question is whether someone with MS risks passing on the condition to their children. People who are related to others with MS - eg cousins, aunts, uncles, siblings - are also concerned about the risks for their children.

MS is not a hereditary disease. It is worth noting that although there are some family clusters of MS, the majority of cases are diagnosed in people with no family history of the condition. The cause of MS is still unknown. Researchers believe that it is likely to be a combination of environment, some genetic element, and some trigger to set off the condition, possibly a virus.

Studies of identical twins show that MS is not directly hereditary. Identical twins share exactly the same genetic make-up, and, in a hereditary condition, if one twin has MS, you would expect the other twin to develop MS. In fact, only around 25% - or 1 in 4 - of identical twins go on to develop MS where the other twin has MS¹.

Researchers in Cambridge have looked at about 600 people with MS and their families, to identify how likely it is that more than one person in a family might go on to develop MS. The comparative risks of developing MS are considered to be²:

- about 1 in 40 for children, brothers, sisters or parents of someone with MS (known as first degree relatives)
- about 1 in 100 for grandchildren, cousins, uncles/aunts, nephews/nieces of someone with MS (known as second degree relatives)
- about 1 in 700 in the general population.

So, if there is MS in the family there is a higher risk for children to develop MS in their lifetime compared with the general population, but this is still quite a low risk overall.

As a comparison, the risk of a person developing cancer in their lifetime is about 1 in 3; the risk of diabetes is about 1 in 33; the risk of any cardiovascular disease is around 1 in 6.

These values only give a guideline. If more than one family member has MS, the risk of children developing MS may vary. If this is a particular concern, genetic counselling services are available on the NHS in some areas - a GP should be able to make a referral.

2. Conception

MS has no direct effect on fertility, which means that anyone with MS has as good a chance of conceiving with their partner as they would have had if they did not have MS.

However, some people experience sexual difficulties as a direct result of their MS. Examples are erectile dysfunction in men, or a reduction in libido for women. These can impact directly on the sexual relationship and thus on the chances of conceiving a baby. The MS Trust's publication, *Sexuality and MS: a guide for women*, explores some of the issues (see section 7), and whilst it can be difficult to discuss these issues, they can be addressed and overcome.

An MS nurse, GP or neurologist may be a good first point of contact, and they should be able to make appropriate specialist referrals if necessary.

2.1 Myths about MS

It is important to dispel some myths about MS and starting a family.

- MS has no effect on the likelihood of miscarriage or stillbirth
- MS does not cause any deformities in the baby, or increase the risk of cot death.

2.2 Taking medication at the time of conception

There has been little research on conception and people with MS. However, it is known that some medications are not suitable during pregnancy, and reviewing medication before trying for a baby may be desirable.

2.2.1 Medication and planned pregnancy

When tested in animals, the beta interferon drugs were shown to cause a higher than normal level of spontaneous abortions (miscarriage) which is why it may be important to stop these drugs early. This finding was confirmed in a recent review of 40 women receiving beta interferons when pregnant. It showed that the rate of miscarriage was slightly higher than normal³. It is recommended that any woman who is taking one of the disease modifying drug treatments for MS (eg Avonex, Betaferon, Rebif, Copaxone, or Tysabri) should stop taking the drugs three months before they start trying for a baby. Women trying for a baby may like to discuss this with their MS nurse. In very rare cases, a neurologist may suggest that a woman remains on disease modifying drug therapy throughout her pregnancy, but this is very much the neurologist's decision which should be taken in partnership with the individual. Similarly, men receiving one of these drugs and trying for a baby should discuss this with their MS nurse/neurologist.

Other drugs used to treat MS symptoms, such as carbamazepine and amitriptyline are not recommended during pregnancy⁴. In some cases, these drugs need to be tapered off rather than stopped suddenly, so it is worth seeking medical advice when considering trying for a baby.

2.2.2 Medication and unplanned pregnancy

If pregnancy is unexpected then it is important to contact a GP and/or MS nurse as soon as possible, to ensure proper care. In addition, some medications may need to be stopped. This should be discussed first as in some cases suddenly stopping drugs may cause unpleasant withdrawal symptoms for both mother and child.

2.3 Difficulties in conceiving

Research shows that people with MS are as fertile as the general population, once sexual difficulties have been accounted for. There has not been any research into other issues with fertility, nor with possible treatments such as IVF.

If there are any concerns about any of these areas, it is worth discussing them with relevant health professionals and asking for appropriate specialist referrals.

3. Pregnancy

3.1 Antenatal care

Antenatal care normally involves frequent monitoring to ensure that all is well with mother and baby. It is important that women with MS ensure that they are happy with the support they receive and keep all their antenatal appointments. A GP or midwife should explain the procedure early on, including rights to time off work and maternity benefits.

The majority of all pregnancies are normal and low-risk, and are managed either by a GP alone, or by a community midwife, or by a combination of GP and midwife care. A recent study showed that having MS does not significantly influence the likelihood of a having a healthy pregnancy⁵.

Researchers analysed a large US database containing information about pregnancies and deliveries in women with MS, epilepsy, diabetes mellitus and the general healthy population. They studied information relating to the following pregnancy outcomes: length of hospital stay; high blood pressure; premature rupture of the sac surrounding the foetus; low birth weight; and caesarean section delivery. Aside from a slightly higher risk of low birth weight

babies and caesarean delivery, MS was not associated with an elevated risk for any of the other pregnancy complications.

3.1.1 Vitamin D supplementation

The role of vitamin D in multiple sclerosis has been the focus of ongoing research. The majority of studies have focused on the role of vitamin D as a protective agent against the development of MS. A campaign fronted by a young Scottish schoolboy whose mother has multiple sclerosis has aimed to raise awareness of the role of vitamin D in reducing the risk of developing MS and other conditions. The campaign goals are to: provide Vitamin D to all of Scotland's children and pregnant mums; to clarify the recommended daily allowance; and to inform the public about the benefits of Vitamin D in relation to MS. The Scottish government has now agreed to launch an education programme with NHS Health Scotland.

Current UK guidance from the National Institute for Health and Clinical Excellence (NICE) states that it is important to maintain adequate vitamin D during pregnancy and breastfeeding, and that women may choose to take up to 10 micrograms of vitamin D a day during these periods, particularly if they have specific risk factors for vitamin D deficiency⁶.

3.2 Effect of pregnancy on symptoms

Most women with MS feel well during their pregnancies, and experience no new problems.

However, some symptoms that occur in MS also occur in pregnancy, and it may be difficult to distinguish the cause. Fatigue is often a problem in early pregnancy and MS fatigue may therefore appear to be exacerbated. Heat sensitivity may also increase during pregnancy, which may contribute to fatigue. Bladder symptoms such as frequency and urgency can increase because of pressure on the bladder from the uterus. In late pregnancy, mobility problems can worsen due to the increasing weight of the baby and changes in posture.

Women's experience of pregnancy is highly variable, and any new or worsening symptoms should be discussed with the midwife, GP or MS nurse.

Some women are concerned about the effect of pregnancy on symptoms postnatally, particularly bladder symptoms. Recent research showed that there was no difference in bladder problems experienced between women with MS who had had children and women with MS who had never given birth⁷.

3.3 Effect of pregnancy on relapses

A very common question among women who experience relapses is whether they are likely to have a relapse during pregnancy.

One study of 227 women tracked them for a year before pregnancy, through pregnancy, and for up to two years after the baby was born. It showed that relapse rates during the early months of pregnancy are unlikely to be very different from normal. However, relapses during the last trimester (months seven to nine) fell markedly. In the first three months following birth, the relapse rate increased to almost one and a half times the average rate of relapses experienced in the last pre-pregnancy year. However, 72% of women on the study did not experience a relapse in that period. The relapse rate remained at a slightly higher level than in the pre-pregnancy period for up to nine months following the birth, but then tapered off to previous levels⁸.

It is thought that relapse rate in women with relapsing remitting MS is reduced during late pregnancy because of the effect of pregnancy hormones, notably oestrogen, which suppress the immune system to ensure that the body will carry a growing baby without rejecting it⁴. Relapse rate after birth may increase because of hormonal disturbances, but there is no consensus about this.

Overall, taking pregnancy and the year following birth as a whole, researchers consider that the number of relapses will remain around the same as it would be if there had not been a pregnancy⁹.

3.4 Effect of pregnancy on progression

There has been limited research into the long-term effects of childbirth on the course of MS. In one Belgian study researchers investigated the progression of disability in 330 females with MS over a period of 18 years¹⁰. Participants were divided into four groups: women who had given birth before the onset of

MS; women who had given birth after the onset of MS; women who had given birth both before and after the onset of MS; and women who had never had children. The time taken from onset of MS to reach point 6 on the Expanded Disability Status Scale (EDSS - a clinical scale used to measure an individual's level of disability) was the measure used to define MS progression. Point 6 on EDSS equates with the inability to walk without the support of a walking aid.

Analysis of the data revealed that women who had given birth at any point in time - either before or after the onset of MS - were 34% less likely to reach EDSS 6 than childless women with MS.

The study authors acknowledge the limitations of their findings, such as lack of consideration for timing and duration of disease modifying drug therapy and the imprecision of the time of MS onset. Further studies are needed before any firm conclusions can be drawn about the effects of childbirth on MS progression.

3.5 MS medications and pregnancy

As discussed in section 2.2, some common medications for MS symptoms are best avoided during pregnancy.

Some people ask whether they are able to receive steroids during pregnancy. Steroids carry some risks and so it is thought that these should be avoided, particularly during the first three months of pregnancy when the foetus is developing very rapidly⁴. However, if a severe relapse occurs, it may be decided - in consultation with a neurologist - that the benefits outweigh any potential risks of treatment.

3.6 Miscarriage

There is no evidence that MS causes miscarriage, although some medications (see above) may increase the tendency. There has not been any research about the effects of miscarriage on MS.

4. Labour and delivery

4.1 Antenatal classes

Antenatal classes are provided by the NHS for first-time mothers, many women may choose to join groups such as the National Childbirth Trust. It might also be reassuring to speak to other people with MS who are pregnant or have given birth in the past. Your MS nurse may know of suitable groups in the local area.

Many pregnant women choose to make a 'birth plan' outlining their wishes for the procedures to be followed at the birth of their child, and where they wish the birth to take place. If at all possible, being attended in labour by a midwife who already knows the woman giving birth, and has experience of their MS, is very helpful. Discussing this with the midwife or GP well in advance of the baby's due date may be useful.

4.2 Effect of MS on labour and delivery

MS does not usually affect labour and/or delivery. There is little research about whether different types of delivery are better suited for MS.

For most women, and for most women with MS, it is thought that a normal delivery is suitable. However, any concerns about positions or managing fatigue during labour may be discussed with a midwife in advance.

At delivery, safety of mother and child is paramount and there may be medical reasons for an assisted delivery - eg forceps or Ventouse (suction cup) - or delivery by Caesarean section. Whilst in some cases, women may choose to deliver by Caesarean section, recovery from this procedure frequently takes longer than from a normal delivery, and involves restrictions on activities such as driving a car and heavy lifting.

Choices about labour should be discussed during antenatal care. Midwives are usually very supportive of a woman's personal choice for delivery.

4.3 Pain relief during labour and delivery

Generally, women with MS can accept most types of pain relief during labour, such as pethidine, entonox (gas and air), epidural anaesthesia. Research has shown that there is no increased risk of relapse from epidural. The NICE

Guideline recommends that women should have the pain relief that seems most appropriate and acceptable to them, without fear of it affecting their MS^{7,11}.

TENS machines are available for pain relief in the early stages of labour. Anecdotal evidence suggests that TENS machines can trigger lower limb spasm in some women with MS during labour¹². It may be worth discussing this with health professionals in advance.

A recent survey of anaesthetists showed that many had little experience of offering pain relief to women with MS, although most would provide epidural or other spinal anaesthesia as a first option. Therefore, it may be worth asking for a discussion with the anaesthetist if a Caesarean or epidural pain relief is planned¹³.

5. Planning for the new baby

Planning can help to make life easier for all new parents. There are two main areas where planning may help:

5.1 Help following the birth

As for anyone with a new baby, it is thought sensible to accept all offers of help. If help is not available from friends and relatives, it may be possible to have formal help arranged, if necessary through social services and/or your health visitor.

If at all possible, try discussing in advance the type of help that might be needed. For example, is help needed with household tasks? Or perhaps with night feeding? Or just taking the baby out to allow some additional sleep in the day?

Help may be needed at different times. Typically, offers of help are received immediately following the birth, but research has shown that the increased risk of relapse remains until around six to nine months after the baby is born. One research study has found that having help available for the whole of the first year reduces the number and impact of symptoms that a new mother with MS experiences, and increases her ability to function normally¹⁴. While this

may not be feasible for everyone, developing a network of potential helpers who may be available at short notice may be useful.

5.2 Equipment

Planning can help when acquiring baby equipment, to see what is available, and what is best suited for day-to-day living, including affordability and how usable it is. For example, many baby car seats are heavy; try to imagine this plus the weight of a baby in one. If fatigue is an issue, pacing the shopping can be important. Going to the shops at quiet times, eg midweek, mail-order/internet shopping and starting the planning process early may all help. In some cases, very specialist equipment may be needed. A midwife or GP can make a referral to the local occupational therapy (OT) service for appropriate assessment, advice, and supplier contacts. There are also a number of useful organisations that provide information and support to disabled parents on various topics, including equipment. These are listed at the end of this factsheet.

6. Life with a new baby

6.1 Feeding a new baby

MS cannot be passed through breast milk and research has shown that breastfeeding is preferable to promote the health of the newborn baby. Only one study has looked at the children of women with MS, and showed that their breastfed babies, when followed for a year, had been less prone to health problems such as ear infections than babies that had been bottle fed¹⁵.

Two small studies have sought to determine whether breastfeeding has any effect on a mother's MS. The first of these studies suggested that breastfeeding might have a positive effect on MS, but the numbers of women involved in the study were too small to be conclusive⁸. More recently, a team of US-based researchers studied 61 pregnant women, 32 of whom had MS to determine whether exclusive breastfeeding protects against relapses in the 12 months after childbirth¹⁶. Just over half of the women with MS did not breastfeed. Of these, 87% had a relapse compared with 36% of women with MS who breastfed for at least two months following childbirth. The protective

effect of exclusive breastfeeding was not diminished when factors such as age, disease duration, pre-pregnancy relapse frequency, and pre-pregnancy treatment were also accounted for.

Also, how to feed a newborn baby is, and should be, a choice. Many women with MS have understandable concerns about breastfeeding. Fatigue can be a real issue for breastfeeding mothers, since only the mother can do it. Bottle feeding can be a shared activity, with other people giving some of the feeds. Also, as discussed in section 2.2, some of the drugs that are not appropriate during pregnancy may need to be started; many of these can be passed on through breast milk and may be harmful to the baby. Therefore, for a variety of reasons, bottle feeding may be more appropriate.

It is important to discuss all these issues with the MS nurse and/or midwife before the baby is born, so that they are able to provide appropriate support and advice. There are also a number of organisations that provide support to breastfeeding mothers, details can be found in section 8.

6.2 Postnatal care

Once the baby is born, the community midwife's duty of care can last for up to 21 days, but is normally less. Care is then transferred to the health visitor, who has a duty to monitor the general health and wellbeing of the whole family, not just the baby. If at all possible, it may be worth trying to meet the health visitor before the baby is born. The GP is also responsible for monitoring mother and baby for around six weeks after the birth.

6.3 Meeting other people

It is easy for anyone to feel isolated when caring for a very small baby. Many people find it helpful to speak to other parents in a similar situation.

The MS Trust has hosted a blog by a woman with MS who gave birth to her first child in April 2009. It charts her experiences through pregnancy and in the months after birth. Visitors can also submit comments to the blog. To access the blog visit the interactive pages of the MS Trust website at:

www.mstrust.org.uk/interactive/babymisme

Health visitors are also good sources of information about local support groups for parents and babies. An MS nurse may be able to help identify other new parents with MS.

Additionally, there are several organisations that offer support and information for disabled parents, listed in section 8.

7. Further reading

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8. Useful organisations

GENERAL

HomeStart

Home-Start UK, 2 Salisbury Road, Leicester LE1 7QR

Website: www.home-start.org.uk

The UK's leading family support charity, offers support in the home from parents supporting other parents. Based on a local network of branches and regions.

National Childbirth Trust

Alexandra House, Oldham Terrace, Acton, London W3 6NH

Website: www.nctpregnancyandbabycare.com

A membership organisation that provides information, publications, networks, ante and postnatal courses and a breastfeeding support service.

Cry-sis

BM Cry-sis, London WC1N 3XX

Website: www.cry-sis.org.uk

A charity that offers support for families with excessively crying, sleepless and demanding babies.

BREASTFEEDING SUPPORT

National Childbirth Trust as above.

La Leche League Great Britain

Website: www.laleche.org.uk

Aims to help mothers breastfeed through mother-to-mother support, encouragement, information and education.

8.3 DISABLED PARENTS' ORGANISATIONS

DPPi: Disability, Pregnancy and Parenthood international

Disability, Pregnancy & Parenthood *international*, National Centre for Disabled Parents, Unit F9, 89-93 Fonthill Road, London, N4 3JH

Website: www.dppi.org.uk

Disability, Pregnancy & Parenthood *international* (DPPi) is a small UK based registered charity, controlled by disabled parents, which promotes better awareness and support for disabled people considering, during and after pregnancy and as parents.

Disabled Parents Network

Website: www.disabledparentsnetwork.org.uk

UK nationwide network of disabled parents, aiming to build up local and national networks of peer support, increase public awareness and work for improvement in services.

Parents with disabilities online

Website: www.disabledparents.net

Useful website for information on disabled parenting. Hosts international peer support and email network of disabled parents.

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